File Haem Dept. AIDS WP

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Minutes of the Third Meeting of the AIDS GROUP of Haemophilia Centre Directors, held at the PHLS Communicable Disease Surveillance Centre on Monday 1st April, 1985.

Present: Dr. C.D. Forbes (Chairman)
Prof. A.L. Bloom
Dr. J. Craske
Dr. I. De'amore
Dr. P. Jones
Dr. P. Kernoff
Dr. C. Ludlam
Dr. E. Mayne
Dr. P. Mortimer
Dr. E. Preston
Dr. C.R. Rizza (Secretary)
Dr. Alison Smithies (DHSS)
Miss R.J.D. Spooner

1. Apologies for absence:

Dr. G. Savidge
Dr. R. Tedder

2. Minutes of the Second Meeting: After amendments had been made to P.3 of the Draft Minutes, the Minutes were approved and signed by the Chairman.

3. Matters arising from the Minutes were covered by the Agenda for the Third Meeting.

4a) Test for HTLVIII Antibody

Dr. Mortimer described the position with regard to HTLVIII testing at PHLS, Colindale. There had been some delay in testing because of their recent move into new laboratories but most of the backlog of tests had now been dealt with.

4b) Commercial Kits

Dr. Mortimer had so far not used the commercial kits and would like to get comparative data on the various kits as soon as

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possible.

The Chairman asked if every local laboratory would be able to buy the commercial kits and do the antibody tests themselves. Dr. Mortimer said that he would advise local laboratories to wait until the kits had been evaluated. It was realised, however, that many laboratories would set up the tests locally within a year in response to demand. He thought it would be necessary to maintain National Quality Control by CPHLS. Dr. Smithies said that the DHSS had written to all the commercial kit manufacturers; 2 firms were now licenced for kits to be used in the UK and 3 more were expecting to be licensed soon. The Department wanted to evaluate the kits and make recommendations to NHS hospitals regarding their use. The number of false positive results were unacceptably high according to the early reports from the USA. The Department hoped all the firms manufacturing kits would take part in the evaluation exercise. Regional General Managers would be informed of the Department's conclusions and it was hoped that all laboratories would take note of the recommendations which should be available by July 1985. The Department hoped that the PHLS Reference System would be used. Dr. Mortimer suggested that repeat tests, using different methods, should be carried out on samples giving a positive result; two positive results with different methods would confirm the results.

4c) Antigen tests

At present there was little information available concerning

tests for HTLVIII antigen. It was hoped that some advances in this field might be reported at the Atlanta meeting on AIDS in April. Dr. Mortimer would report back to the next Meeting.

5. Reporting of HTLVIII Antibody Test Results

Dr. Craske said that Dr. Tedder and Dr. Mortimer would let him have a copy of the test results at the same time as sending the results to the Haemophilia Centre Director who had sent the sample. They were still getting the system finalised but hoped it would be fully operational in about one month's time. All of the results, would be stored and analysed in Manchester.

There was the same discussion concerning the reporting of AIDS cases and HTLVIII antibody results to CDSC? It was pointed out that CDSC only required a weekly report to enable them to work out a tally of the positive results and regional trends. Collection of data by CDSC would show over weeks and years the spread of the infection Nationally. Concern was expressed that misleading information might be sent to CDSC if all positive results were sent in as the results of tests for many patients apparently showed changes from positive to negative then back to positive. After discussion it was agreed that repeat tests should be done on all positive samples and if these were positive the result should be reported to CDSC on the yellow forms 30C (available from Dr. Galbraith) a copy of the yellow form should be sent to Dr. Craske. Clinical cases of AIDS should be reported to Dr. McEvoy on her Form 30, using code letters and numbers to identify the individuals (CDC System). ARC cases should continue to be reported to Dr. Craske on his blue Form

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AIDS/3 as at present. Dr. Craske and Dr. McEvoy would liaise over the AIDS and ARC reports, recommending new forms if they felt this would be advantageous. Dr. Craske would report back to the next meeting after discussion with Dr. McEvoy regarding the forms. It would then be necessary to discuss the matter at the next meeting of all Haemophilia Centre Directors and if they approved, to send the necessary forms to all Directors. There was some concern amongst members about changing the system of collecting the data so soon after it had been introduced.

The possibility of ARC cases in haemophiliacs being included in the weekly CDSC Reports were discussed. It was thought that it would only be useful to report to CDSC the clearly defined cases.

6. New Cases of AIDS and ARC

Dr. Craske reported that one new case of AIDS in a haemophiliac had been reported to CDSC. The patient was a mildly affected Haemophilia A patient in whom the diagnosis had been made retrospectively. Details of the case in particular the histological data were not yet available and were being followed up by Dr. Craske. The patient had received only one transfusion, in 1981, when he had received 3 different batches of concentrate.

Dr. Jones presented confidential data regarding the Newcastle patients and Dr. Ludlam agreed to circulate to Group members a pre-print of a paper he had presented at a recent BSH meeting. Dr. Forbes referred the Group to a paper published in the JAMA (253, 1571 (1985)) giving data on the spouses of

HTLVIII+ patients.

7. Up-date on Laboratory Testing

Dr. Forbes referred to the problems of factor VIII and factor IX deficient substrate plasma required for laboratory assays and it was agreed that it was not wise to use HTLVIII+ plasma as substrate.

Professor Bloom said he had written to Dr. Tyrell to express the Directors concern over the stringency of the ACDP interim guide-lines on AIDS and had been informed that a Working Group had been set up to look into the problem. Professor Bloom had been invited to join the Group as representative of the UK Haemophilia Centre Directors at a meeting to be held in June. It was agreed that all Directors should write to Professor Bloom as soon as possible giving their opinions on the guide-lines and a note of any difficulties they were encountering in local laboratory practice as a consequence of the guidelines.

Dr. Smithies was asked to give the DHSS's views regarding staff who were HTLVIII+ and what the consequences of a positive result would be for the member of staff. Dr. Smithies said the problem was being considered by the Departments Advisory Group but believed there would be no difficulties over compensation. Dr. Smithies agreed to put her comments in writing. She could not give advice about HTLVIII+ staff continuing to work in hospitals.

8. Clinical Problems

The difficulties over nursing of HTLVIII+ patients was discussed. The procedures for Nurses have already been laid out in the RCN guidelines. It was agreed that Dr. Jones would ask

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Sister Fearns to draft a document which could be discussed at the AIDS Group's next meeting.

9. Local Committees for AIDS advice

Dr. Forbes said that a local committee had been set up in Glasgow and had been overwhelmed by requests from people who wanted to be involved. Discussion revealed that local committees had also been formed in Oxford, Cardiff, Manchester and Newcastle.

10. Information

i) Literature: The Chairman distributed an information package to each member of the Group.

ii) Symposia: Attention was drawn to 2 forthcoming meetings one to be held on 3.4.85, sponsored by Abbott and another to be held in Glasgow on 11th June.

iii) Media: No discussion took place.

11. A.O.B.

No additional matters were raised.

12. Next Meeting

Monday 20th May, at the Royal Free Hospital starting at 11.00 a.m.

The meeting finished at 4.15 p.m.